Hemochromatosis – Iron Overload Disease

WHAT IS THE PUBLIC HEALTH PROBLEM?

- Hemochromatosis, the disease that occurs as a result of excessive absorption of dietary iron, affects over 1 million Americans. Undiagnosed hemochromatosis affects an unknown number of additional people because its early non-specific symptoms often go unrecognized. Serious health effects include arthritis, cirrhosis of the liver, liver cancer, diabetes, heart abnormalities (leading to heart failure), impotence, infertility, and death from the associated chronic diseases.
- Early detection of hemochromatosis among adults enables treatment to begin before severe organ damage has occurred.
- Treatment by periodic removal of iron (by blood removal or phlebotomy) is safe and effective and can lead to a normal life expectancy, if initiated before organ damage has occurred.
- Education aimed at clinicians and other health care providers is needed to heighten their awareness of the importance of early diagnosis and treatment of hemochromatosis, thus reducing the patient and economic burden of the disease.

WHAT HAS CDC ACCOMPLISHED?

CDC's current research included collaborative studies to: 1) more precisely determine how many people have gene mutations for hemochromatosis and the number of people at risk of developing disease symptoms; 2) characterize how hemochromatosis affects a person's health over their lifetime; 3) assess the risks and benefits of screening for the early detection of hemochromatosis; and 4) evaluate whether diagnostic tests for iron overload performed by different laboratories yield equally accurate results.

Example of program in action: The goal of CDC's "*Clinician and other health care provider education on hemochromatosis*" is to create a high-quality, scientifically based, reliable, respected educational resource for primary care physicians and other health care providers who are most likely to see patients with undiagnosed hemochromatosis. A web-based, self-study format was selected as a cost-effective way to reach physicians and other health care providers at their own convenience (24/7). CDC, in collaboration with experts from related medical fields, developed the training course content materials emphasizing the importance of early diagnosis and treatment of patients with hemochromatosis. The interactive course includes modules on epidemiology, clinical features, diagnostic testing, treatment and management, and family based detection. To further leverage existing resources, CDC's Public Health Training Network will provide assistance in dissemination of the course and in awarding continuing medical education credit.

WHAT ARE THE NEXT STEPS?

CDC will launch a campaign to disseminate its on-line training course, "Hemochromatosis: What every clinician and health care provider needs to know." Physician education also will be conducted on-site at medical society meetings, and through a partnership with managed care organizations, CDC will evaluate the impact of the training by measuring patient outcomes. CDC also will explore existing data sources to determine the proportion of hemochromatosis within other diseases (i.e., diabetes, arthritis, heart disease, liver cancer); evaluate the natural progression of symptoms and signs of iron overload that lead to the more serious complications; determine prevalence within minority populations; and compare the costs and benefits of various screening strategies. Research also should determine the role of iron-fortified foods in the onset of hemochromatosis and develop evidence-based dietary recommendations for patients.

For information on this and other CDC programs, visit www.cdc.gov/programs. *February 2003*